

## ESSAY/PERSONAL REFLECTION

# The clock: Not a question of time

ALBERTO GARCÍA-SALIDO M.D., PH.D.,<sup>1</sup> AND R. MARTINO-ALBAR, M.D., PH.D.<sup>2</sup>

<sup>1</sup>Pediatric Intensive Care Unit, Hospital Infantil Universitario Niño Jesús, Madrid, Spain

<sup>2</sup>Pediatric Palliative Care Unit, Hospital Infantil Universitario Niño Jesús, Madrid, Spain

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Pedro\* was a four-year-old boy diagnosed with neuroblastoma. He lived in a town near the Madrid airport. I had just finished my fellowship in critical care in pediatrics and I decided to work in pediatric palliative care as a way to complete my training about end-of-life care.

We met Pedro a few days before his hospital discharge. There were no more “curative” therapies. The main objective turned to achieve his comfort at home. We were a dark vision to his parents. As the palliative care team, we were the carriers of the end.

We first explained our focus to his mother. While this conversation was taking place, his father was looking through the window. It was his way to escape every time we were near. We did not exist for him. At the same time, to Pedro, we were the opportunity to get back home. No worries or question about his disease. We were the chance of seeing again Optimus Prime in his never-ending battle with Megatron. We discontinued and changed some drugs. Later, we trained both parents to take care of their son at home. After one week of changes, Pedro was discharged from the hospital. We made our first visit to his home one day later.

And there was Pedro, in his bedroom with his toys. He was in his world, far away from us in many ways. We started our standardized first visit protocol, almost an hour of explorations and explanations. First of our patient and second of his house. We tried to find potential traps and problems. In this search, we find it: his clock.

“It has been there since he was an infant, we do not remember how it came but there it is.” his mother said.

And there it was, in front of his bed. At the height of our eyes, the clock’s second hand was moving back and forward trapped in a moment, over and over. We asked Pedro about it.

“So you have a broken wheel-clock?”

“No,” he answered seriously. “It is a perfect wheel-clock; my mother says life is not only a question of time.”

After this answer, we looked each other. Later we asked him permission to make a photo of his clock (Figure 1).

“I am sure it will be famous,” he commented with a smile.

We scheduled one visit per week and 24/7 phone assistance. We explained that the parents could phone us at any time; we would be there if needed. We traced a care plan based on what Pedro needed. Our psychologist asked Pedro about his wishes and desires. As we usually say: treat the person, not the disease.

Pedro maintained a stable situation for a month. Because of his pain, we initiated morphine. We also treated his constipation and helped to move him outside his house. He went to the park, to the burger shop, or to the cinema. He was surprised because we did not take blood tests.

“When are you going to make me a new blood tests?” he asked sometimes.

“Do you need them to play?” we usually answered.

At each visit, we always checked the wheel-clock. It was always frozen in the same seconds. In some ways, inside his bedroom, we spent a month without time.

The phone rang early in the morning. Something had changed in Pedro and his mother said just these four words: “He is not awake.”

We arrived there as soon as we were able. All of us knew that these changes were going to come because they always come. When we saw him we realized that there was a different Pedro. He was almost asleep, lying down, with both eyes closed.

Address correspondence and reprint requests to: Alberto García-Salido, Pediatric Intensive Care Unit, Hospital Infantil Universitario Niño Jesús, Avenida Menéndez Pelayo 65, Madrid, Spain 34915035900. E-mail: [citopensis@yahoo.es](mailto:citopensis@yahoo.es)

\*The patient’s name and identifying characteristics have been changed to protect his privacy.



“I am sure he needs a transfusion,” his father said.

After the physical examination, we went to the living room. We explained to the parents that Pedro had entered the final phase of his disease. His father left the house. We said what he knew but did not want to hear. Her mother stayed in silence and went to the bedroom with her son.

There were difficult days. Pedro was not able to leave the bed. He suffered pain, dyspnea, fever, and constipation. We treated each symptom. The perfect adjuvant therapies were his parents’ voices, the Transformers cartoons, and his toys. We made daily visits to adjust the therapies. His house was full of friends and family. We tried not to be an interference. After a week from the first phone call, we received a new one.

While we were going to his house, we saw some planes take off. It was night so their lights turned into moving stars. We stayed in silence.

His father was in the street. We entered into the house and turned left to go into Pedro’s bedroom. Pedro was in his very last moments so a new exploration was not needed. We touched his face and he smiled.

His parents had placed the nasal cannula with a low oxygen level; we decided to maintain it for a moment. Then we talked in the living room to explain about what was happening. Not many words were needed. Pedro was comfortable. After a diminishment in consciousness, the oxygen was removed. We decided to leave the house and wait outside. The door was opened by his father, who looked at us in the eyes for the first time.

We helped them with all the bureaucracy and waited for the funerary services. But first we made a last visit to Pedro. His mother was inside the bedroom sitting next to him. We expressed our condolences and she smiled.

“Don’t forget the clock,” she said.

We took our medical equipment and just before closing the door, we looked at it.

The clock had started to move.

We left the house without asking her about this change. As we went back to the hospital, we discussed it. We conclude that it was a trick; a mother deciding to stop the time by hacking it through a clock. And maybe she did it because Pedro will be always with us. After all, life and living, as somebody said, is not just a question of seconds, is not a question of time.

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## CONFLICT OF INTEREST

None.